

Minutes of
The Public Health Data Standards Consortium (PHDSC)
Steering Committee Meeting
March 21-22, 2001
Arlington, Virginia

Wednesday, March 21, 2001

Welcome and Introductions – Marjorie S. Greenberg, Chief, Data Policy and Standards Staff, CDC/NCHS

Ms. Marjorie Greenberg chaired the 2nd Annual meeting of the Public Health Data Standards Consortium. She welcomed participants and expressed the hope that this meeting, besides providing much learning in data standards, would yield a Consortium work plan for the next several years ahead. She thanked the meeting sponsors, namely, the Centers for Disease Control and Prevention (CDC), the National Electronic Disease Surveillance System (CDC/NEDSS), the National Center for Health Statistics (CDC/NCHS), the Agency for Healthcare Research and Quality (AHRQ), the Association of State and Territorial Health Officials (ASTHO), the Department of Health and Human Services (HHS), the National Association for Public Health Statistics and Information Systems (NAPHSIS), the NCHS staff, and the meeting logistics contractor, the Native American Management Services (NAMS), for making this meeting possible.

Marjorie briefly reviewed the background of the Consortium, from the first planning meeting of January 1999 to its present status of a coalition of thirty organizations. She highlighted some of the Consortium's accomplishments over its short period of existence, namely, the formation of a Steering Committee, approval of the Consortium's operating principles, identification of high priority data elements from a NAHDO study and the formation of workgroups to address several of these data elements. This year, the Consortium financed a study to develop an Education Strategy, the purpose of which is to build partnerships and educate constituencies, to participate in the development of national standards and to support implementation of those standards. This study would be the focus of the meeting's afternoon discussion.

Marjorie also highlighted some of the work and successes of the Consortium within the Standards Development Organizations (SDOs) and the Data Content Committees (DCCs). One was the approval by ANSI ASC X12 of the Department's request to change the institutional guide to allow for the collection of race/ethnicity on the 837 claim. The Consortium had worked on this issue and was able to assist the Department with the business case. Also, at the X12 June 2000 meeting, the Consortium received approval to add mother's medical record number to the 837 claim and encounter standard. This year, at the February meeting, Bob Davis received approval for the Consortium to develop a Health Care Services Data Reporting Implementation Guide. Finally, by participating in the Designated Standards Maintenance Organizations

(DSMO) process through membership on the NUBC and NUCC, and also through the X12-837 work group, the Consortium has been able to assure that some data elements critical to public health and research will remain in the HIPAA implementation guide.

Finally, Marjorie stressed that partnerships between the federal and state levels are absolutely critical, the Consortium being representative of these partnerships and of strength in numbers.

E-Codes Workgroup Presentation – Andye Zach, Acting Deputy Director, Health Policy and Planning Division, Office of Statewide Health Planning and Development, Sacramento, California *and* J. Arturo Coto, Disease Surveillance Coordinator, Office of Epidemiology, Nebraska Health and Human Services.

Ms. Andye Zach and Dr. Arturo Coto both co-chair the E-Codes work group. Andye presented the update on the group's activities.

The group first needed to evaluate the current practice of E-codes collection in the various states, then assess and propose the steps necessary to improve the E-code reporting in discharge data systems and in the electronic reporting standards. The workgroup first studied the NAHDO recommendations to expand the required primary diagnosis fields in the X12 standard to accommodate two additional diagnosis fields, namely, place of occurrence and adverse events. Several other reviews, specifically, APHA, NAICRS, NHTSA/Codes, revealed much variation in the collection of E-Codes. Andye stated that, to satisfy the requirements of ICD-10, a minimum of 3 fields would be necessary - one for the cause, one for the place, and one for the activity. Presently, the E-Codes work group needs to finalize a business case to provide justification for the designated field for place of occurrence and designated field or fields for additional E-Codes. Andye also stressed the need for education so that providers, practitioners and users will be able to accurately and completely use the data available.

Payer Type Work Group Presentation – Amy Bernstein, Director, Development and Analysis Group, Division of Health Care Statistics, CDC/NCHS *and* Susan Elder, Director, Center for Health Information Management and Evaluation, Association of State and Territorial Health Officials, Missouri.

Dr. Amy Bernstein and Ms. Susan Elder presented the activities of the Payer Type Work Group. Amy acknowledged that a standard source of payment code is necessary to compare one data set to another in evaluating the impact of payment on public policy. However, on investigation, there is presently no national standard. The group therefore, after having looked at several code sets, formulated a code set that can allow for the possibility of rolling up to the highest level so that one can get to a lowest common denominator when comparing datasets. Amy presented this code set and pointed out the importance of balancing the needs of evaluating policies or doing research against what is realistic to collect.

Susan expressed the need for more input and feedback to assess the feasibility of this typology and whether or not there are payers that have not been included. Decisions also must be made as to ownership of this typology. So far, during its conference calls, the group has decided not to take this case to the X12 work group, feeling it may be better to have it externally maintained. Susan then entertained questions from the audience. Meeting participants suggested the Consortium collaborate with those groups that collect this information for their assistance in determining its feasibility and to aid in implementation. Participants also liked being able to roll up the code set to different levels of specificity. Marjorie encouraged comments on the Plan ID when its notice of proposed rule making is scheduled.

Mother's Medical Record Number Work Group – Suzie Burke-Beebe, Health Informatics Specialist, CDC/NCHS

Ms. Burke-Beebe presented the report for the Mother's Medical Record Number Work Group. She outlined the process of presenting a request to ANSI ASC X12 to add this data element to the 837 claim. She gave credit to Bob Davis, who began developing a business case for this data element since November 1998. Then, at last year's Consortium meeting, a workgroup was formed to continue the process. Suzie and Bob forwarded the request to X12 in June 2000, and, after several stages of the process, approval has been granted and will be published this month. Suzie further elaborated on the X12 process and the various groups to which a request must be presented for approval prior to its acceptance. Suzie expanded on the networking that needs to be done in distributing the information, building the business case, reviewing it, and packaging it. Also, networking goes on within X12 at the Task Group level, the Architecture Group level, and various other workgroups within X12N. After Suzie had presented this update, Marjorie reiterated the role of the Consortium in presenting requests for changes to the standards stressing that not all need to know the technical aspect but that all can contribute to developing the "business case".

Final NAHDO Report on Priority Encounter Data Elements – Denise Love, Executive Director, National Association of Health Data Organizations, Utah.

Ms. Denise Love presented the final report of the Encounter Data Prioritization Project started by NAHDO in October 1999. The preliminary report presented during the Consortium's 1st Annual meeting in March 2000, had sparked the formation of the E-codes, Payer Type and Mother's Medical Record Number workgroups. As a starting point, the data elements were limited to discharge data systems due to the impending impact of the HIPAA implementation on these systems. Denise reported there are at least 44 states collecting inpatient discharge data, and that outpatient data systems are increasing. At least 15 states are collecting emergency department data. Data sources were the HCUP inventory of 1998. Common state fields were identified and cross-walked to the 837 and the UB92.

Literature reviews were conducted for selected fields and prioritization of data elements done. Data elements recommended for Consortium action are E-codes, County Codes,

Race/Ethnicity, Source of Payment, and Mother's Medical Record Number. As stated previously, the Consortium has been active in pursuing several of these data elements. A second group of data elements are those with unresolved issues and to which more study is needed before a business case can be deployed. Another group of data elements are those that already have standard definitions but need to be incorporated into the data sets of the SDO's.

Denise stressed that states will definitely benefit from uniformity but there is a great need for education and technical assistance to implement HIPAA even at the basic level. Meeting participants discussed also the collection of EMS run number and race/ethnicity as very important elements but that collection and reliability issues need to be addressed. The practical utility of the information, i.e., how it is used and its measure of importance must also be considered. It was acknowledged that some data elements may not be perfect but can still be useful. Also addressed was the need to define a common set of business rules that will govern the collection efforts for the data elements, setting standards for consistent collection. Denise concluded by suggesting the group consider whether or not any new workgroups need to be started to address any specific data element.

Panel on States Initiatives--Implications for Public Health:

SPARCS and HIPAA – Robert Davis, Director, Statewide Planning and Research Cooperative System, New York State Department of Health.

Mr. Robert Davis presented on the on-going changes within the SPARCS system in New York in response to the HIPAA legislation. Though public health is not directly affected by the HIPAA rules, public health receives many of its data from the hospital discharge system, thus rendering this entity as users of the HIPAA standards. Therefore, Bob advised that public health must get involved in the process of making changes to the standards. He cited the recent examples of neonatal birth weight, last menstrual period, and taxonomy codes that some felt were not necessary, yet were very essential for Medicaid. Bob praised the HIPAA legislation for providing the impetus for partnerships within public health and the health care industry.

Bob highlighted several Consortium activities in the SDO's, especially the approval of ANSI ASC X12 for the establishment of a Health Care Data Services Reporting Implementation Guide. The name is intended to portray a bigger picture than just public health. He stated this guide would be a user-friendly technical document to provide standard implementation for data standards that use or potentially could use the 837-claim transaction standard. Bob thanked the New Jersey Health Department, The New York State Department of Health, the National Uniform Billing Committee (NUBC) and the Washington Publishing Company (WPC) for their present role and support of the guide.

Bob further explained the rationale for this guide. He stated that there are some claims-related data elements from the 837 that are totally consistent with the HIPAA transaction guide. There are other data elements such as diagnosis, demographics, e-codes that also are necessary for public health reporting. These are in the guide for payers and providers to do the business of HIPAA. Then there are several codes in the standards that we need but they are not in the guide. Therefore there is need for a guide specific to the data elements necessary for health care reporting.

Bob intends to have this Guide written within the next six months to one year and requested help among the Consortium participants and other members of the Consortium organizations.

Health Care Information Networks and Technologies – Marilyn Dahl, Senior Assistant Commissioner, New Jersey Department of Health and Senior Services.

Ms. Marilyn Dahl described the New Jersey's Health Care Information Networks and Technologies (HINT) as a vision for using electronic technology to increase health care efficiency and reduce administrative cost. This legislation was enacted in July 1999 and was effective in December 1999. It aligns closely with the federal HIPAA legislation but requires standardization of both paper and electronic transactions and formats. Upon the adoption of HIPAA electronic standards for health care transactions, the Department of Banking and Insurance was required to adopt by rule a timetable to implement and comply with certain of the administrative simplification electronic transaction standards. These rules were published on March 5th for public comment, with adoption expected in late summer. Marilyn went on to describe the initiatives of the Local Information Network and Communication System (LINCS) that utilizes the PC and Internet technology to connect the New Jersey Department of Health to 115 local health departments. The primary goal is to support communicable disease and biohazard surveillance, as well as rapid response.

Another initiative mentioned is the redesign of the New Jersey Discharge Data Collection System, which uses the 837 standards. Marilyn stated all New Jersey acute care hospitals would begin using this new system by March 31, 2001. Much positive feedback with cost savings has been reported so far. This system will be expanded to collect emergency department and outpatient data. She also reported on the use of the electronic death certificate within the state of New Jersey, thanking the state of New York for providing the software for this project.

Health Key – W. Holt Anderson, Executive Director, North Carolina Healthcare Information and Communications Alliance (NCHICA).

Mr. Holt Anderson reported on the Health Key Consortium, which comprises five states, namely, Minnesota, Massachusetts, Washington State, Utah and North Carolina. This is a project funded by a Robert Wood Johnson grant for developing a vision of how health information may be protected using the Internet, and for implementing pilot projects

using clinical data to prove this out. Representatives of these states present in the audience were Walter Suarez, Minnesota; and Elliott Stone, Massachusetts. Others are Jan Root and Bart Killian, Utah; and Elizabeth Ward and Bill Campbell, Washington State. Holt elaborated on the need for timely and comprehensive access to patient information but in the context of privacy and security, addressing issues of unauthorized access, identity theft, information theft, and misuse or breach of privacy. He stated policies and procedures must set the foundation but these policies must be instituted and operationalized by technologies and operational procedures. Holt explained the need for collaboration and a sense of shared responsibility in light of common trading partners and business associates.

Further explaining the Health Key Project, Holt stated there are currently 14 projects, some involving immunization records, and others involving standards for data collection and emergency department electronic information interchange. He urged public health to work collaboratively to build a road map that will fit also with the private sector so data elements can be exchanged securely.

Uniform Data Standards for Patient Medical Record Information - Jeff Blair, Vice President, Medical Records Institute.

Mr. Jeff Blair explained the role of the National Committee on Vital and Health Statistics within the HIPAA legislation, stating the committee was given the responsibility of studying and making recommendations to the Secretary of Health and Human Services regarding uniform data standards for patient medical record information. Having held many hearings and listened to numerous testimonies from different stakeholders within the health care industry, the Committee has summarized the impediments to the ability of sharing clinically specific health care information to the lack of interoperability between computer systems, lack of comparability of data, and inadequate data quality.

Committee recommendations were to formulate criteria for the development and coordination of standard data elements, vocabularies and terminologies, facilitating experts' involvement. It also recommended that government funding be made available to assist with implementation guides, conformance testing, research to improve clinical data capture, and the coordination of broader initiatives and incentives to equitably distribute cost of implementation. Jeff emphasized that, complementary to these efforts, legislation must be in place to ensure the privacy and security of patient medical record information. This report of the National Committee on Vital and Health Statistics was submitted to the Secretary in July 2000 and is on the NCVHS website (www.ncvhs.hhs.gov).

Presentation and Discussion of Draft Education Strategy – Caroline Steinberg, The Lewin Group; Christina Andrews, The Lewin Group; Denise Love, NAHDO; Marjorie Greenberg, CDC/NCHS; Walter Suarez, Minnesota Health Data Institute (MHDI).

The afternoon session of the 2nd Annual Public Health Data Standards Consortium Steering Committee meeting was devoted to the presentation and discussion of the Draft

Education Strategy. This Educational Strategy Report is the product of a contract between the National Center for Health Statistics and the Lewin Group along with NAHDO. Acting upon recommendations at its first annual meeting, the Steering Committee of the PHDSC established an Education Work group to address such topics as education, communication, public relations, HIPAA implementation, technical assistance, and user-friendly data dictionaries. The Lewin Group and NAHDO worked in conjunction with this Education Workgroup to develop the proposed strategy.

The goals of the Education Strategy were presented. The primary goal was to articulate why public health databases should migrate to existing standards and why public health needs to engage in data standards activities in general; to identify the audiences for educational outreach; to identify what partners the Consortium should work with to develop educational content as well as to implement the plan; to identify what data-bases exist at the state level and what standards apply to those data bases.

Ms. Caroline Steinberg described the framework for the project. The Education Strategy is divided into three phases, with specific activities in each phase. Activities among phases can overlap, as priorities of Consortium work are set. The purpose of this meeting was to discuss and prioritize the activities of the proposed Consortium Educational Strategy for both the short and long term.

The methodology used for this study was interviews and literature reviews done by both the Lewin Group and NAHDO, and case studies of selected state databases performed by NAHDO. Ms. Denise Love, NAHDO's Executive Director, reported on her interviews of the public health leaders who are maintaining these systems. She stated interviewees believe the Consortium could bring diverse groups together to create a vision and serve as a bridge between programs and sectors in public health. The Consortium can also help public health participate in the national standards process and support and strengthen current public health national standards initiatives bringing experts together around data systems. During her interviews, Denise was able to divide the many responses into broad categories of roles that the Consortium could play to various organizations in the promotion of data standardization. These roles are advocacy, convener, voice and resource. She then expanded on these roles. As an advocate, the Consortium can help public health articulate the rationale for data standards. As a convener, the Consortium is bringing many organizations together around data standards issues. As a voice, the Consortium has been representing public health at the Standards Development Organizations and the Data Content Committees, and as a resource, the Consortium seeks to educate and support the implementation of data standards. However, Denise acknowledged the great economic challenges and the variations of state regulations and information policies. Denise summarized solutions into categories of funding and technical assistance, partnerships and education. Discussions that followed emphasized the need for public health to keep true to its perspective of using data standards to improve the health of the public and not sway to full focus on the business side.

Ms. Marjorie Greenberg then led a discussion regarding the roles of the Consortium, specifically as an advocate, convener, voice and resource as outlined by Denise. She

wanted the group, as Consortium members, to more concretely define the role that the Consortium should play both now and for the future. She questioned the role in which the Consortium is most needed and where it can make the greatest impact. She also requested that the audience identify where the Consortium is least needed and whether there are other roles not presently defined. It was the consensus of the group that the Consortium would not play all roles in all cases. Participants acknowledged that many of the states have different needs. In some instances, the Consortium may be just a supporter or would acknowledge the existence of data standards activity; in other instances it would have to take a lead where there is no voice of public health. Another role discussed is for the Consortium to facilitate in defining data elements and justifying the incorporation of those elements in whatever standardized list is chosen. Marjorie acknowledged that the Consortium is not seeking to stop any innovative data standardization process and cannot realistically be involved in all activities. It will be present where needed. Participants concluded that, with its limited resources, the Consortium should be a resource to identify where data standards is needed, what are the benefits of standards, and how to advance data standardization, being always mindful that the “business” of public health is keeping people healthy and making them healthier. One suggestion for education was the preparation of core presentations to be adjusted to the level and needs of the various audiences. Thus a consistent message can be disseminated to different groups depending on their needs. Marjorie also discussed the proposal of a clearinghouse as a means of coordinating data standardization activities within public health to ensure non-duplicative efforts.

Ms. Caroline Steinberg and Ms. Christina Andrews further explained the phases of the Education Strategy. The first phase involves building partnerships and educating constituencies. The Consortium cannot accomplish its goals without extensive involvement of various entities involved in public health and health services research and the organizations that fund the practice of public health. These include legislative bodies and government agencies, as well as foundations. Phase Two involves participating in standards development, working with organizations to organize public health and research communities to effectively represent their interests on standard setting bodies. Phase Three involves the implementation of standards.

The activities of each phase of the strategy were discussed. The proposed activities of phase I are to strengthen educational partnerships, coordinate educational activities with NEDSS, reach out to other partners, secure funding, raise awareness and motivate participation. Proposed activities of the phase II strategy are to post summaries of “What you need to know”, recruit and train public health representatives to serve on SDO’s, engage a community around a particular data system and develop a web based clearing house on development of data standards. Proposed activities for phase III are to create an implementation guide of selected standards, create an implementation toolbox, and develop a web-based clearing house to track data integration and standards implementation efforts in public health. Several barriers to these strategies were also presented along with the audiences to whom the particular strategy is intended.

After some discussion, Dr. Walter Suarez engaged Consortium meeting participants in prioritization of potential Consortium activities by voting. Highest priorities for 2001-2002 were determined as: strengthen educational partnerships, coordinate educational activities with NEDSS, secure funding, develop a Web-based resource center to track standardization efforts, post summaries of “What you need to know”, and develop a web-based resource center to track data integration and standards implementation efforts in public health. Highest priority for future years is the creation of an implementation toolbox.